
Reflections on Cultural Difference And Advance Directives

by Vicki Michel

Advance care planning cannot assume a single meaning of autonomy. Even when autonomy is apparently employed in the traditional white, middle class, American sense, personal interviews uncover nuances that are based on cultural differences.

When congress passed the Patient Self-Determination Act at the end of 1990, it was acting out of a conviction that people generally want control over their health care when they are no longer capable of decision making, and that having documentation of a person's wishes would avoid conflict and litigation of the kind that resulted in the *Cruzan* case that had been decided by the United States Supreme Court in June of that year. It was assumed that the small number of people who had signed advance directives was a result of lack of information about them, a situation the PSDA tried to remedy by creating health care institutional obligations to give information to patients. However, people have not embraced the opportunity to create advance directives in large numbers. It is now appropriate to look again at the assumptions that drove the view of advance directives as a cure-all for decision-making dilemmas involving noncompliant patients.

Although discourse about advance directives has been around for awhile, it has recently developed a critical edge, particularly with respect to the version of autonomy that underlies arguments in favor of such documents. In the past few years, data regarding cultural differences have been available to support the critique.

In September, 1990, the American Society of Law and Medicine and several other organizations sponsored a conference that explored the

implications of the United States Supreme Court decision on the *Nancy Cruzan* case. Two conference presentations raised significant reservations about advance directives. In a talk titled "The Authority of Families to Make Medical Decisions for Incompetent Patients after the *Cruzan* Decision," Patricia King said:

I suggest that making formal, written plans based on individual preferences apart from our families is a white, middle-class approach to life planning that is at odds with how many people actually lead their lives and may not even be the standard for that class. It discriminates against cultures and individuals who, both through necessity and choice, look to their families ... to take care of their interests when they are no longer able to do so (King 1991).

In another presentation, Joanne Lynn, MD, commented that "I, and surely some other patients, prefer family choice over the opportunity to make our own choices in advance" (Lynn 1991). She further indicated that her own seriously ill patients do not seem very concerned about the possibility that next of kin might make choices that are different from what the patients would have chosen themselves (Lynn 1991).

In December, 1991, the *New England Journal of Medicine* published a special report titled "Sources of Concern about the Patient Self-

Determination Act" (*Special Report* 1991) signed by many bioethics luminaries. The report focused on reservations about advance directives, both treatment directives and proxy appointment directives, but there was no mention of cultural differences as a concern and the authors come down strongly in favor of directives despite some differences about their use.

Writers in the bioethics field haven't seemed to consider that anyone would take issue with the fundamental proposition that human beings care about being in control of their lives both in the present and in the future when they may no longer be able to express their preferences. Reservations concerning the documents focused more on whether advance directives were respected by health care professionals, rather than on whether having them was consistent with people's desires at the outset.

Moreover, bioethicists provided little support from the "real world" for their assumptions about the primary importance of personal autonomy. Empirical research on advance directives was superficial and done on very limited populations. Physicians, philosophers, theologians, and lawyers who dominate the field appeared to have little familiarity with the theory or methodology of the social sciences, and to this day many bioethicists have little knowledge of or respect for the work of social scientists, especially the relevant and significant work being done by medical anthropologists.

Arthur Kleinman offers a thoughtful critique about those aspects of the field that limit its ability to grapple with the role of advance directives. He writes:

The bioethicist, of course, is supposed to take into account the patient's perspective. But by and large, the contextually rich, experience-near-illness narrative is not privileged: It is reinterpreted ... from the professional biomedical standpoint in order to focus exclusively on the value conflicts that it is held to instantiate (Kleinman 1995).

Part of Kleinman's discussion is a critique of individualism, which he points out does not govern the thinking of some eighty percent of the planet's population (Kleinman). But in addition, he notes that "there is also a failure to take into account the local worlds in which patients and practitioners live, worlds that involve unjust distributions of power, entitlements, and resources."

This critique thus goes beyond the theoretical communitarian critique of the individualism of western liberal political theory and forces us to confront real lives, including the uncomfortable issues of power and oppression in our own history. These issues move from abstraction to concrete context when we look at research involving the attitudes and behaviors of African-Americans in relation to advance directives.

A research project at the University of Southern California had striking data not inconsistent with, but more dramatic than, earlier studies. We interviewed 800 individuals, ages sixty-five and older, who identified themselves as being in one of the following four ethnic groups: African-American, Korean-American, European-American, and Mexican-American (200 in each group).

In the first year of the study, we used an hour-long questionnaire; in the second year we did in-depth ethnographic interviews with ten percent of the first-year participants.¹

Data collected the first year indicated that African-Americans tended to have a positive attitude about advance planning for end-of-life decisions, significantly more positive than Korean- or Mexican-Americans. Four questions were used in creating the attitude score. Participants were asked if they agreed or disagreed with four statements such as "It is best to avoid talking about serious illnesses or death before they occur."

African-Americans tended to disagree with this kind of statement, thus evincing a positive attitude toward advance planning. However, despite this positive attitude and despite having English as their primary language, African-Americans had significantly less knowledge about

advance directives than Mexican-Americans and European-Americans. (African-Americans: 12%; Mexican-Americans: 47%; and European-Americans: 69%) and only 2% of African-Americans had advance directives. These are significantly lower figures than those of European- and Mexican-Americans. No Korean-Americans had advance directives.

The low knowledge level of African-Americans, even for those who lived at a site that offered educational seminars on advance directives, was a surprise. We concluded that different groups "may be differentially motivated to seek out information actively" (Murphy 1996). Perhaps we should not have been surprised. Marian Gray Secundy, in calling attention to the history and condition of Blacks in America, suggests an explanation:

In the midst of this reality, the mainstream conversations about dying in America seem somewhat surreal ... Most Blacks do not trust the medical establishment and are not comfortable with issues related to advance directives (Secundy 1997).

This lack of trust is well founded in history, and it is unlikely that President Clinton's belated apology for the Tuskegee Syphilis Study and like attempts will extinguish it.

One can find awareness of the impact of history in clinical literature. For example, in a discussion of autonomy in the context of working with elderly African-Americans, the authors point out:

In a society where personal freedom has been denied and efforts to attain freedom have been met with substantial resistance by others, including recognized civil authority, the willingness to share personal preferences and to make decisions based on these preferences may be limited ... For older groups with a history of oppression, attempts at self-determination or self-expression have been met with violence in the past (Mouton et al. 1995).

In addition, part of what oppressed groups experience is difficulty in access to the health care they need. Why would anyone who has struggled to get care be willing to sign a document limiting care? As Professor Secundy points out, "Blacks are suspicious and distrustful that they will not receive fair and equitable treatment, that their organs will be harvested prematurely, that their lives are expendable because they are raised uninsured" (Secundy 1997).

Conscious of this history and experience, we are forced to recognize that the differences we discover in studies like the USC study should not be viewed as uncovering inherent differences between races or ethnic groups. Rather, the differences seem attributable to contexts in which we develop our values and our views of the world. While this study and others indicate that persons in other cultures value personal autonomy less and family relationships more than Americans typically do (Blackhall 1995), it does not follow that we can predict someone's attitudes or values by knowing their ethnic backgrounds. Research that explores cultural difference can result in undesirable stereotyping, a danger to avoid.

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Despite the fact that European-Americans in the USC study had positive attitudes toward advance planning and the highest level of knowledge of advance directives of the groups studied, only a minority had a document. None of the groups were homogeneous with respect to their attitudes and, in fact, anthropologists remind us that despite the convenience of "culture" as a way to talk about differences, it is *heterogeneity*,

not homogeneity, that characterizes groups we identify as "cultures."

The difficulty of capturing the complexity of beliefs and preferences about end-of-life care in the answers to a questionnaire or in an advance directive emerged in the second year of the USC study. An interview with a Korean-American subject, Mrs. Kim, illustrates this point. Mrs. Kim "believes that medically futile treatment should be avoided and would not want it for herself" (Frank forthcoming). However, if she were making a decision for a close relative, she would try to keep the person alive as long as possible. Moreover, she would expect her children to do the same for her. As she put it, "I am the one who is going to die so I don't control the situation" (Frank forthcoming). When asked whether this was contradictory, she acknowledged that it was, but "it's the right thing to do. Don't you think so? Would any children let their mother die without trying to save her by any means?" (Frank forthcoming).

What, then, would Mrs. Kim want at the end of her life — that her preference for no treatment if she were terminally ill be followed, or that her children do everything to keep her alive? The full context of the interview indicates that it is important to Mrs. Kim that her children behave properly to a parent (filial piety). This may take precedence over her personal preferences.

Our focus on autonomy leads us to ask "But what does she *really* want?" The question is too simple, and expecting to discover easily what people *really* want by simply asking them does not do justice to the complexity of beliefs and our way of reasoning about end-of-life decisions. In Mrs. Kim's case in particular, that expectation does not take account of her apparent belief that her own preferences are not as important as her need to have her children "do the right thing." For some people in some cultures, obligations that are inherent in and constitutive of relationships are primary, rather than individual rights. Although not a new concept, it is a difficult one to capture in the kind of advance directives to which we are

accustomed. Even a proxy directive doesn't seem adequate. As Joanne Lynn points out, "For many Americans, making a unitary designation is contrary to the family's history of making conjoint decisions and imposes the possibility of generating an unnecessary discord...." (Lynn 1991).

What, then, is to be learned from studies that examine advance directives in the light of cultural differences? First, attention to differences helps us be conscious of and learn to cope with the complexity and ambiguity that is characteristic of our lives. Ethnographic interviews from the second year of the USC study focused attention on the complexity of the ways in which people think about end-of-life decision making (Frank forthcoming). In her beautiful, rich book, *Peripheral Visions*, Mary Catherine Bateson says, "Ambiguity is the way of life, not something to be eliminated. Learning to savor the vertigo of doing without answers or making do with fragmentary ones, opens up the pleasures of recognizing and playing with pattern, finding coherence within complexity, sharing within multiplicity" (Bateson 1994).

Our expectation regarding advance directives is that there is a way to get it right. As Richard McCormick says, "We are obsessed with being in charge" (McCormick 1997).

But it may be that the best we can do is respect the people with whom we interact and do the best we can: "Living in a society made up of different ethnic groups offers a paradigm for learning to participate without knowing all the rules and learning from that process without allowing the rough edges to create unbridgeable conflict" (Bateson 1994).

Endnotes

1. For a full description of our methods, see Blackhall et al. 1995.

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